

Hazardous Substance Disease Clusters

Definition: Group of events occurring unusually close together to each other in time or space, in both time and space, or within the same demographic group (for example, persons in the same occupation)¹

Summary

In a one-year period during 1994 and 1995, Washington State Department of Health epidemiologists responded to over 25 inquiries from citizens and groups concerned about possible disease clusters (see definition).

These clusters of disease are typically chronic diseases (for example, cancers and birth defects) suspected to be associated with exposures to hazardous substances in the environment. Many hazardous substances are known to cause chronic disease conditions, but if the link between environmental exposure and specific cases of disease has not been previously documented, it is extremely difficult to establish.

Time Trends

As the public becomes more concerned about the risk of disease from environmental causes, it is expected that there will be a corresponding increase in the number of inquiries and requests for cluster investigations.

These investigations are time-consuming and expensive, and the communities are sometimes not happy with the results. Many of the health conditions linked with environmental exposures can be associated with a number of different factors (for example, smoking, diet, heredity); therefore, it can be extremely difficult, if not impossible, to establish what is causing the illness or disease.

Year 2000 Goal

The goal for the year 2000 is to investigate 100% of the disease/illness clusters reported to be related to exposures to hazardous substances.

Geographic Variation

The map on this page depicts the location of field investigations of disease/illness clusters.

Race, Ethnicity and Income

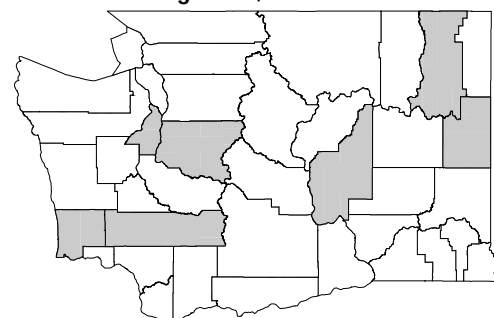
Data are not currently available on reports of disease/illness clusters by race, ethnicity or socioeconomic status. However, concern has been expressed that some racial minority groups and people of low socioeconomic status may receive disproportionate exposures to environmental contaminants and that, subsequently, they may experience a higher than expected frequency of health effects from such exposures.²

Disease/Illness Cluster Reporting

Clusters can be characterized by time (for example, higher than expected number of cases identified in a period of time), or place (for example, communities, schools, workplaces), or a combination of the two (for example, five new cases of leukemia diagnosed in one year among students who attend the same school). Anyone can report a cluster of disease or illness. These reports may come from concerned citizens, local health departments, health care providers, and community activists. Key information collected to facilitate cluster investigations includes:

- Setting of the cluster (for example, school, neighborhood, workplace).
- Nature of the perceived problem.

Hazardous Substance Disease Cluster Investigations, 1993 - 1995



■ Counties in Which Cluster Investigations Have Occurred

- Type of symptoms or illnesses in excess.
- Period of time the symptoms/illness occurred.
- Geographic boundaries of the alleged cluster.
- Suspected cause of the symptoms/illnesses.

Disease Cluster Investigations

Clusters of disease/illness can occur randomly in a population without explanation. Clusters are investigated to determine if a preventable cause exists, though it is very difficult to establish a link between an environmental exposure and disease. Investigations are usually fairly lengthy (minimum of 3 months).

Considerations when investigating clusters include:

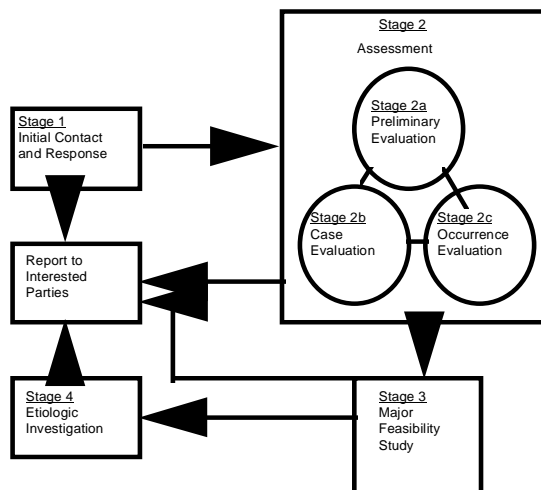
- A successful cluster investigation in which the cause of the cluster is identified may not be possible. The investigation can be just the first step in determining causation.
- The actual cause or causes of the disease/illness may not be identified or known.
- Investigators may be unable to demonstrate geographic or temporal excess of cases from available health data.
- Data may be unavailable on many exposures that occurred in the past.
- Affected persons may not have lived in the area long enough for an exposure to a hazardous substance in the environment to have occurred.
- Cancer is a common disease which increases in occurrence and frequency with age. It is not a single disease, so each type of cancer must be examined as a different health outcome.
- Major birth defects are less common than cancer but still occur in 1 to 2% of live births.
- A variety of diseases and illnesses in a community does not necessarily mean that there is a common exposure.
- Other risk factors for the disease condition are also evaluated.

Procedures for investigating clusters of health events³

1. Define the cluster.

2. Find cases.
3. Examine actual and potential exposures.
4. Assess biological plausibility
5. Analyze disease/illness rates.
6. Compare risk of disease/illness among exposed individuals versus nonexposed.
7. Determine the significance of the cluster.
8. Report results.

Diagram of Disease Cluster Protocol⁴



Disease Cluster Investigative Team

In the investigation of a disease cluster, a multidisciplinary team is developed to examine issues regarding the cluster. A typical team might consist of:

Health care provider - Examines medical history, diagnosis and case definition.

Epidemiologist - Determines the appropriate health study, develops health questionnaire, if needed, and analyzes health statistics.

Toxicologist - Evaluates the biological plausibility and toxicity of the suspected causative agent.

Public health advisor - Identifies and quantifies hazardous substances in the air, water, soil and land.

Health educator - Establishes a health risk communication system for the community.

Local Health Department Health Officer or Representative - Provides input on local health and other issues pertinent to the investigation. Serves as a point of contact for the state with the local health agency.

Intervention Points, Strategies and Effectiveness

The initial investigation may not answer all of the questions that a cluster raises. Moreover, the burden of investigating the cluster may outweigh its actual public health significance.

Communication is an important response to these issues. It should be managed by a health psychologist or other risk-communication specialist, particularly in answering questions and discussing and interpreting the findings of the investigation. Risk perception and risk communication will influence the community's opinion of the outcome of the investigation.

Epidemiologic Surveillance Systems. Data from the cluster investigation can be used to begin tracking the occurrence of disease in the population that was studied to examine the number of cases in the community over time. Incidence of the cases of disease that were originally identified as a cluster may continue to occur at a higher than expected rate or may begin to decrease at some point in time. In either case, this information can provide extremely useful etiological clues.

An epidemiologic surveillance system can be also used to track the health status of communities at high risk of exposures to environmental agents. These communities are selected based on known point sources of environmental contamination within or directly adjacent to the community.

Disease Cluster Electronic Database.

Centralization of the reports of clusters through an electronic database accessible by epidemiologists and toxicologists in state and local health agencies would minimize the potential for duplicate investigations and give investigators the most up-to-date information on current and past cluster studies.

The Role of Media. Risk communication is an integral part of the investigative process. Communication is important so that citizens understand the public health response to a perceived cluster. Issues must be discussed in a clear and open manner. Alternatives to full investigations which can be undertaken by agency staff or even the community need to be presented. When full investigations have occurred, it is important to discuss and interpret the findings in a public forum. People trained in risk communication are helpful in developing approaches that create an atmosphere conducive to

open dialogue in a language that can be understood by all. In addition, publicizing the study may assist in finding additional cases of disease that were not previously identified. To ease fear and anxiety in the community, the media can publish the preliminary findings of cluster investigations.

For More Information

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Endnotes:

¹ Last, JM (1988) *A Dictionary of Epidemiology*, 2ed., New York: Oxford University Press, p 25.

² Johnson, BL, Williams, RC, Harris, CM, National Minority Health Conference: Focus on Environmental Contamination, Princeton: Princeton Scientific Publishing Co., Inc., 1992.

³ Centers for Disease Control (1990): Guidelines for investigating clusters of health events. *MMWR* 39(No. RR-11):1-22.

⁴ Fiore BJ, Hanahan LP, Anderson HA (1990): State Health Department response to disease cluster reports: A protocol for investigation. *Am J Epidemiology* 132:514-522.